

Table of Contents

Letter from the Director, Office of Genomics and Disease Prevention, CDC	1
SNPets from CDC.....	4
I. Public Health Research	
Chapter 1	
The Role of Human Genomics in Acute Public Health Investigations: Current Practice and Future Strategies	7
Incorporating Human Genomics into Acute Public Health Investigations	
• Examples of Investigations • APhi Workshop Held in May 2004 • Conclusions from APhi Workshop • Current Public Health Research Priorities	
Chapter 2	
CDC's Family History Public Health Initiative: 2005 Update	11
Family History for the Public • U.S. Surgeon General's Family History Initiative • MMWR • Family Healthware™ • Evaluation Study • Public Health Research	
Chapter 3	
Genomics and Vaccine Safety: Research for Future Practice.....	15
Need for Vaccine Safety Research • Current Vaccine Safety Research at CDC • Integrating Genomics into Vaccine Safety Studies • The Future of Genomics and Vaccine Safety	
Chapter 4	
Direct-to-Consumer Marketing Campaign: Genetic Testing for Susceptibility to Breast and Ovarian Cancer	19
The Direct-to-Consumer Marketing Campaign • Public Health Significance • The Complexity of BRCA1 and BRCA2 Testing • BRCA1 and BRCA2 Tests Are Not Appropriate for Most Women • Direct-to-Consumer Advertising • Public Health Response • Survey Development • Consumer Survey Results • Provider Survey Results • Conclusions	

II. Genetic Testing

Chapter 5

ACCE Reviews of Genetic Tests: <i>BRCA1</i>, <i>BRCA2</i>, and <i>CFTR</i>.....	27
Introduction to ACCE • The ACCE Review Process • Family History and <i>BRCA1</i> and <i>BRCA2</i> Mutation Testing to Identify Women at Risk for Inherited Breast/Ovarian Cancer • Preconception and Prenatal Screening for Cystic Fibrosis via <i>CFTR</i> Carrier Testing • Lessons Learned	

Chapter 6

Evaluation of Genomic Applications in Practice and Prevention: Implementation and Evaluation of a Model Approach.....	35
What is the EGAPP Project? • The ACCE Project • Why is Evaluation of Emerging Genomic Applications a Public Health Issue? • EGAPP Working Group • Stakeholders • Other EGAPP Activities • Expert Meeting on Evidence-Based Review of Genomic Applications • Why Might EGAPP Project Activities Interest State and Local Public Health Professionals? • How Will Success Be Measured?	

Chapter 7

Newborn Screening for Cystic Fibrosis: A Public Health Response	41
What is Cystic Fibrosis? • Why Test Newborns for Cystic Fibrosis? • Public Health Response • Weighing the Costs and Benefits for Universal Newborn Screening for CF • Adding CF Screening to Existing Newborn Screening Programs • Challenges in Implementing CF Screening • Laboratory Implementation Issues • Follow-up and Communication Issues • Conclusion	

Chapter 8

Enhancing Genetic Testing for Rare Diseases: Improving Availability, Access, and Quality	49
Genetic Testing for Rare Diseases • What is a Rare Disease? • Public Health Implications of Improving the Translation of Rare Disease Genetic Testing • Promoting Quality Laboratory Testing for Rare Diseases: Keys to Ensuring Quality Genetic Testing • Public Health Actions: Improving the Translation of Tests for Rare Diseases from Research to Clinical Practice • Public Health Actions: Ensuring Access and Quality of Rare Disease Testing	

III. Public Health Practice

Chapter 9

Centers for Genomics and Public Health: An Update 55

University of Michigan Center for Genomics and Public Health • University of North Carolina Center for Genomics and Public Health • University of Washington Center for Genomics and Public Health • Centers' Collaborative Activities • Summary of the Centers' Activities

Chapter 10

Developing State Capacity for Integrating Genomics into Chronic Disease Prevention Programs: An Update 65

Michigan Department of Community Health • Minnesota Department of Health Chronic Disease Genomics Project • Oregon State Genetics Program • Utah Department of Health: Chronic Disease Genomics Program • Summary of the States' Activities

Appendices

Appendix A: Genomics Internet Resources for Health Professionals 79

Appendix B: Coalition of State Genetics Coordinators..... 93

List of Authors 103